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ABSTRACT

This paper presents an overview of how American libraries have responded to the health crisis caused by HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome). AIDS information dissemination practices of libraries and the social role which American librarians have articulated regarding their special responsibilities are discussed. Libraries and their use of community health information services, library extension programs, and information and referral services to promote access to HIV-AIDS information are considered. An overview is provided of federal government policies regarding HIV-AIDS information, especially the establishment of information programs designed to bring information to the general public, such as the national AIDS Hotline and other program operated by the Centers for Disease Control, the U.S. Public Health Service, and the National Library of Medicine. Examples of special HIV-AIDS libraries and information centers are discussed, including the AIDS Information Network of Philadelphia and the AIDS Committee of Toronto. Typical library models of services suited for the delivery of HIV-AIDS information which have evolved in American libraries are also considered. (Contains 13 references.) (Author/MES)

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HIV-AIDS Information and the American Library Community: An Overview of Responses to the HIV-AIDS Health Crisis

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Paper presented at the Conference

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HIV-AIDS and the American Library Community: An Overview of Responses to the HIV-AIDS Health Crisis

L'Information sur le VIH-SIDA et la communauté des bibliothécairs améicains: une vue générale sur la réaction à la crise de la santé et du HIV-SIDA

Presented at the conference "Les Bibliothèques Face au SIDA" Paris, France, December 12-13, 1996

ABSTRACT

Paper presents an overview of how American libraries have responded to the health crisis caused by HIV and the AIDS disease. Discusses AIDS information dissemination pratices of libraries and the social role which American librarians have articulated regarding their special responsibilities. Considers libraries and their use of community health information services, library extension programs, and information and referral (I&R) services to promote access to HIV-AIDS information.. Provides an overview of federal government policies regarding HIV-AIDS information, especially the establishment of information programs designed to bring information to the general public such as the national AIDS Hotline and other programs operated by the Centers for Disease Control (CDC), the U.S. Public Health Service, and the National Library of Medicine. Examples of sspecial HIV-AIDS libraries and information centers are discussed including the AIDS Information Network of Philadelphia and the AIDS Committee of Toronto. Typical library models of services suited for the delivery of HIV-AIDS information which have evolved in American libraries are also considered. Includes references. Three version of the paper are provided-- the longer, more detailed version, an abbreviated version, and a French language translation of the longer version. WBL

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HIV-AIDS Information and the American Library Community : An Overview of Responses to the HIV-AIDS Health Crisis

I. Introduction and Background

Thank you very much for the opportunity to share some of my thoughts and observations with you regarding how American libraries have reacted to the need for AIDS information and the need to cooperate with other social agencies in seeing that the public receives this vital information. I commend you for presenting this conference. I was very impressed when I received this invitation and read the outline for the program which involved a joint meeting of librarians and HIV-AIDS experts. To the best of my knowledge, I know of no such a meeting having been held in the United States on a national or even a regional scale. I look forward to returning to the United States with new insights and a renewed enthusiasm for the work which lies ahead.

As you know, AIDS is one of the leading causes of death in major metropolitan areas of the United States today. By 1995 it was the major cause of death of American of ages 25 to 44; and as of December 1995, slightly over 300,000 Americans had died of AIDS complications from a pool of just over half a million cases diagnosed since 1981.[1]

Although HIV infection and the AIDS disease have become phenomena of global and historic proportions, reports of its spread can be confusing. An article carried by the Knight-Ridder Newspaper service in September of this year (1996) inferred from government statistics that in the United States AIDS's effect had been primarily personal and not cultural. The same article noted that the disease is predictable and that its transmission is largely the result of male-to-male sexual activity. The article went on to say that it has forced an open dialogue in society which probably would never had occurred had we not had this crisis. The author, Mary Ann Lindley, reported that this dialogue has opened up American society and forced us to face many health and social issues in non-traditional ways. As a result, she believes that gays and lesbians have come to be seen generally as more human; blood transfusions are now safer; patient rights in general have increased with people demanding more health research and better health information; and Americans now tend to see the drug abuse problem more as a health issue rather

than a criminal issue. From my own observations, I feel that American society has become much more compassionate regarding those afflicted with HIV and AIDS.

Nevertheless we must not think that this crisis is over although deaths and infection rates among gay men in particular appear to have stabilized. A recent Centers for Disease Control (the CDC) report warned that one in 300 Americans now carries the HIV infection and that close to three-fourths of those infected have not yet been diagnoses with AIDS. Dr. John Karon of the CDC warns that the United States will face a very substantial medical and public health problem for years to come.[2] The CDC is a part of the U. S. Public Health Service and it is the federal agency which has been given primary responsibility for combating the AIDS-HIV disease.

In addition to the medical and health issues involved, conflicts of values and attitudes and believes about personal behaviors such as sexual and drug abuse activities have become a part of public debate in the United States. Many of these conflicts and issues have become political issues and they have influenced and will continue to influence how American libraries respond to this crisis.

In my talk today, I hope to address several of these pressing issues. I shall begin with a brief overview of the social obligation which libraries as institutions have in this crisis. In 1991, librarian and social observer, Judith Segal wrote that libraries have a serious social obligation to respond in positives ways to the AIDS health crisis.[3] To bolster her point, she noted that several social researchers, working independently of librarianship, have identified the American public library as an important source of information for several groups of people, including Afro-Americans and Hispanics.[4] This recognition is important because these two groups are minority groups within American society which carry a disproportionate share of infections for both men and women when compared to the general population. Segal also mentioned another study in her article which claimed that some 35 percent of people who were surveyed in Connecticut considered the public library to be a primary source of AIDS information.[5]

The New York Library Association was among the first professional American library association to recognize the social and cultural role which libraries could play in this plight. In 1988 they issued a broad statement concerning the position of New York libraries in the battle against AIDS. Along with recognizing the need for information, the association was especially concerned with the

problems of censorship of materials and services. They noted that school libraries were especially venerable to censorship due to the nature of the AIDS disease and the types of information needed to explain it and to fight against its spread.

Looking at the American scene from social and demographic perspectives, there are good reasons to support the social involvement of librarians in the fight against AIDS. Lowel Lewin, a public health educator, in a speech to the American Library Association in 1987 listed several reasons for this. He explained that they are:

Local and familiar to most Americans

Offer free services

Provide a collection of materials considered legitimate

Convenient in location and hours of operation

Non-judgmental in terms of users and topic of interest to users

Socially natural, apolitical, stable, and continuing.

In essence, he believed that the American public library is a trusted institution which has little competition in terms of providing access to hard-copy health information.[6]

Nonetheless, it seems to me that American libraries in general have not really found the special niche which they might occupy within the mixture of HIV-AIDS educational and information services now being provided by schools, the mass media, health care providers and agencies, and community-based organizations. Research and observation continue to say that American libraries are underutilized by the American public as a source of HIV/AIDS information. The information is available in libraries through books, periodicals, videos, and pamphlets; but the public does not often think of the library as a place to first go for AIDS information. At least in the early days of this crisis, many people seemed to perceive it more as a medical problem with questions needing to be answered by medical experts.

Research has also shown that librarians themselves have some ambivalence and inertia regarding their role in providing AIDS information. A 1987 survey found that public librarians were unsure whether information was then available at the level of understanding needed by the public. They were

also unsure about the range and level of information to provide and they believed that most of their requests for AIDS information would come from school-driven assignments.

A study I conducted in 1990 of public library directors serving medium-sized city libraries (which I defined as cities of 200,000 up to one million in population) indicated that this ambivalence still exited. I found that essentially directors were willing to acquire materials on AIDS but they were not willing to consider this need to be much different from any other information need and they did not to give it special attention.

This perception that the AIDS crisis is just one crisis among many must be taken seriously. Some years ago, a public librarian in Milwaukee reminded me that the AIDS health situation was just one among several with which the city had to deal, including a rise in teen-age pregnancies. She felt that it was unreasonable to expect her library as well as other libraries to devote special attention to this one social problem..

She was right to some extent.. Many libraries in the United States face a very hostile political climate and an unsure funding base. Public financial support for libraries is stagnate at many levels of government at a time when social needs are great and when public expectations are high. Clearly good choices have to be made.

In discussing AIDS information, there is sometimes an assumption made that people who are at high-risk for contracting AIDS cannot be expected to use libraries for information.. Diana Gonzáles Kirby and Tony A. Harvell , who are librarians themselves say that it is unclear whether targeted high-risk groups such as intravenous drug abusers and their sexual partners, and gay and bisexual men are groups which are visiting libraries. They suggest that libraries can best serve non-high risk users who need AIDS information.[7] We have little information about drug users and their library use, but we might argue that from general use patterns and educational levels that American gay and bisexual men and lesbians as a group are potentially strong users of library-based information systems. Economic and social data concerning the American gay and lesbian population show that many gay and lesbian people are well educated and affluent and command attention as a powerful consumer and political group. In 1995 Grant Lukenbill, who is not related to me, wrote a book on how businesses could best gear-up for a

coming explosion in gay and lesbian consumerism.[8] Historically, increases in affluence and education generally suggest increases in public library use.

II. AIDS Information Dissemination

With that background given, I would like now to discuss some of the major ways that HIV-AIDS information is distributed in the United States and to explain how libraries have or have not been involved in these dissemination efforts.

In doing this we cannot overlook the broader picture of AIDS education. Lacking a cure for AIDS related diseases, information and education seem to be the only real solution in prevention of HIV infection and AIDS.

Mark Hochhäuser and Jame Rothenberger, health educators, say that there is a difference between AIDS information and AIDS education. Education, they claim is directed toward changing attitudes and behaviors, while information is the communication of facts or data. They claim that information suffers in the fight against the AIDS disease because it is random and is not generally placed within a relevant context. In other words, it offers no system in and of itself for initiating and maintaining attitude and behavior changes. Education, on the other hand, while it relies on information, is more dynamic because it can focus on changing attitudes and behaviors. They believe that education programs and campaigns which focus only on facts and information will have little effect on changing crucial attitudes and behaviors.

If these views are correct, libraries will need to be more focused in their information delivery strategies and aim at developing programs and services which can directly influence attitudes and behavior changes. I feel that libraries as systems are able to do this. Information which comes into libraries is not random. It is ordered through classification and indexing schemes which places it within a context of other related information . The reference services and other forms of public services found in American libraries can further this by placing this information into the life context of the person making the inquiry.

In addition to reference services, within American libraries, certain programs and services appear to be especially suited to help place AIDS information into context and thereby to promote attitude

and behavior change. Some of the more dynamic services which have the potential for influencing behavior and attitude change include: consumer health information services; extension and outreach programs, and community information and referral services. I shall briefly review each of these services and offer my views as to how they can place AIDS information into the context of the user.

Community Health Information Services

I shall first begin by discussing American libraries as providers of consumer health information . Consumer health information is defined as information intended for the layperson. It is not specialized, technical information created for medical professionals. As such, American libraries have provided this type of information for years on an informal basis. A librarian-colleague of mine who is taking a degree in public health administration tells me that in the 1920's some public libraries were formally allied with public health agencies in the fight to combat public health problems of that time. Unfortunately the history of the movement has been lost and forgotten. Nevertheless, within recent decades many public libraries have begun to pay more attention to consumer health information largely as a result of public demand and expectat. . . . AIDS and HIV information naturally falls with this consumer health paradigm.

Formal consumer health information programs generally provide these services: bibliographic services (that is, delivery of materials); on-line computer searching; resource development; interlibrary loan; information and referral; special programming; publications service; networking and resource sharing; and union catalog project development. Because consumer information is expensive most of the larger programs in the United States and Canada are cooperative efforts undertaken by library systems, library networks, or several individual libraries working together in a formal partnership.

In an interview with a consumer health librarian for the King County Library System, located in Seattle, Washington state. I was told that while the center does not make an effort to maintain a special collection of AIDS materials, the topic is a part of their overall collection development plan and they will respond to questions about AIDS with all the consideration they give other requests.

A similar operation is run by the Prince George's County Memorial Library System located in Maryland.. This library system is located just aside Washington, D.C. and it is a large metropolitan

system. It is so large that the system is divided into districts for administrative purposes. One of its district libraries holds the consumer health information center which serves the whole county-wide system. According to its director, it too will respond to AIDS information upon request.

A neighboring library system, the Montgomery County (Maryland) Department of Public Libraries, also located outside Washington, D.C. likewise provides consumer health information services. Several year ago it conducted a survey which I think shows why most large public library systems have not moved to establish especial AIDS information centers. Initially the library had developed a rather intense level of HIV-AIDS information services, but after they conducted a user survey about health information needs they found that most users were interested in general health issues, and not so much in specialized AIDS information. With that in mind, they scaled back their initial services and developed a more inclusive consumer health information center.

School libraries have traditionally collected health information especially as demanded by the curriculum and the developmental needs of students. However, little has been published about them. With regard to AIDS, what we do find published in literature are bibliographical essays and lists of HIV-AIDS materials suitable for school library collection.

Some months ago I talked to a high school librarian in my home city of Austin, Texas about the kinds of programs and services she offers or has offered concerning AIDS information. She said that her services focuses on helping students find information about HIV-AIDS as related to school assignments. She has developed special lists and finding guides to help students find suitable materials in her collection. On occasion she has created and presented exhibits and bulletin boards especially related to special school events or national observations such as National AIDS Awareness Day.

One development in school libraries which may have an impact on the AIDS information in schools is the new concept of the school neighborhood health clinic. This idea promotes the locating of a public health clinic in low-income neighborhood schools. The concept behind this is that parents will pay more attention to the health of their children and to themselves if a center is located in a safe and convenient place. The major thrust of the center is to promote preventative medicine where basic care is given and where advice and information can be readily obtained. A few month ago, I talked with an

Austin elementary school librarian about how she collected materials to support a neighborhood health clinic located in her school. She told me that AIDS materials are collected along with other types of health information, but she must be very careful to see that materials on all subjects do not offered user by being too sexually explicit and too revealing in terms of human anatomy. This cautionary approach is in part a response to the fact that such medical centers are controversial. Some people feel that they will provide birth control information and abortion information to students without parental control. Albeit, the potential for censorship of AIDS information faces all school libraries, not just libraries serving school with neighborhood health clinics.

In the early days of the AIDS crisis academic libraries such as the University of California at Berkeley, outside of San Francisco devoted some attention to developing AIDS-information awareness among its students and faculty. These activities not only included preparing AIDS information bibliographies and finding guides, but involved having library staff members go out into the academic community to speak to student groups and to take part in other public information campaigns such as health fairs. These activities have lessened as HIV-AIDS information has become more available. Some academic libraries, as well as other libraries have presented work-place AIDS workshops to inform their staffs about the crisis. These workshops include such topics as how to avoid infection and how to interact with those who are infected. Legal issues and responsibilities are also discussed in these workshops.

In terms of helping librarians better deal with AIDS information, some libraries and library cooperatives such as the Regional Library Cooperative, Central Jersey, located in Freehold, New Jersey have conducted workshops and held other forms of in-service training to help librarians better deal with HIV-AIDS information resources.

Library Extension Programs

Let me now discuss library and extension programs and how they have been involved with and supported HIV-AIDS information delivery. Over the years many American public libraries have developed outreach and extension program. These programs usually operate to provide library materials and services to people and organizations outside their usual service locations. The programs usually concentrate on users and locations which are hard to reach such as housing projects, health care centers,

juvenile homes, and jails. Although the possibility is there, it appears that only the more innovative libraries have made much use of library extension and outreach services to provide specific AIDS and HIV information services.

However, one outstanding example of an extension and outreach innovative program was developed by the Memphis and Shelby County Public Library System located in Tennessee. Jean Hofacket, who was then head of extension services for the library developed this program and I think it is an excellent model of an extension program which emphasizes HIV-AIDS information . Although Ms. Hofacket is no longer with this library system, she nevertheless continues this work at the AIDS Information Network of Philadelphia, where she is director of information services. I will discuss this network later in my talk.

While Jean was in Memphis, she and her colleagues went out into housing projects with AIDS information packets, they met with drug users in various settings telling them how to use the public library, and they made special effort to contact and meet with gay and lesbian groups around the city. In addition, they produced a number of television programs designed to be shown on public access cable channels in Memphis. This was all possible I think because the Memphis Shelby County Public Library has had a long history of supporting extension and outreach programs. I must say that the Memphis program is an exception and that few American public libraries have become this involved in AIDS information delivery.

Information and Referral (I&R) Services

In recent years information and referral (I&R) and community information programs located in public libraries have expanded the types of information available to the public. This kind of service places an emphases on services and local information available in and unique to a specific community. Although a relative new service, some American libraries have made it a part of their fundamental service program. We know that many HIV-AIDS requests for information centers around obtaining services for the care and support of those who may be suffering from HIV-AIDS. It is therefor obvious that a community-wide community information services for providing this as well as and other kinds of HIV-AIDS information is necessary. Guidelines issued in 1989 by the Community Information Section of the

American Library Association suggested that information and referral services in libraries can be rather extensive and involve assistance beyond simple information delivery. Recent developments suggest that more attention should be paid to locating information about human service agencies in the community; job information; Spanish language services; and HIV-AIDS support services.[9]

A US-MARC record format for community information was published in 1992 and some libraries such as the Montgomery (Maryland) Department of Libraries now use this format to list community information on their on-line public access catalogs (OPACs). Naturally, library OPACs which are available through the Internet and which use the MARC community information format will further expand the availability of AIDS information to the community.

School libraries have long recognized the importance of community information, although they generally have not used the terms" Information and referral." As far back as 1949, Margaret Rufsvold discussed the role which school libraries could play in identifying, recording, and making available community information to their users.[10] Later writers on school library management have continued this advice;[11] and in 1990 the Texas Education Agency issued a manual on how to develop a community resource file for school libraries.[12] In the 1980's an interesting field-based research project was conducted by the British Library to see how best to teach student how to use community information. This project discussed how to better involve the school library in the dissemination of community information and it provided some good practical examples of how the program could be implemented.[13]

Although the concept of community information located in the school is a workable and a good idea; at least in American school libraries, it can create problems when HIV-AIDS information in concerned. The current social climate in the United States is volatile regarding values surrounding sexual conduct, youth and information about sexuality. Because HIV-AIDS is very much a part of sexual behavior, controversy and conflict of values surrounding this fact has and will continue to impeded the implementation of community information within school environments.

Part III. Libraries and Government Policies

Most of the industrial countries of the world have national AIDS-HIV policies involving medical, legal, educational, and economic aspects of this disease. Similar to other countries, American policy is

based on the assumption that correct information is necessary to stop the spread of HIV infection. In the mid-1980s the Public Health Service of the United States outlined a plan for informing and educating the American public about HIV and AIDS. The plan included mass-media campaigns, health education programs, demonstration programs, establishing an AIDS information clearinghouse, and the developing of special information for use by AIDS educators. The department identified four major information and education efforts or populations to be addressed. These included: the general public; 2) school and college-aged populations; 3) persons at increased risk for infection; and 4) health workers.

The initial campaign was started in 1987 and was called "America Responds to AIDS. It was designed to reach the general population with vital information about how to prevent infection. Since that time the campaign has moved from meeting an immediate crisis to one of combating a chronic problem. As I mentioned earlier, the Centers for Disease Control (CDC) has the responsibility for the management of this program. Basically the program is channeled from Washington through state and local government health departments. Although a strong information component is contained in this program, I feel that the program does not sufficiently recognize the role that libraries can play in disseminating AIDS-HIV information to the public. The way grant guidelines are written libraries would have a difficulty time meeting criteria for funding. The guidelines are clearly written in favor of health agencies and other similar community-based organizations.

Nevertheless, the federal government has developed some programs which do benefit libraries in terms of making certain types of information available to them. One of these is the National Library of Medicine (NLM). The library's AIDSLINE offers a great deal of scientific and professional information to libraries and community-based organizations who can afford it or who can otherwise qualify for it through varies means. NLM also has a program in which it offers small grants to libraries to encourage them to develop innovative health information programs. Libraries might be able to tap into this resource to fund AIDS-related programs but to my knowledge few if any have done this.

The National AIDS Information Clearinghouse is another resource which libraries can use to gain information. The Clearinghouse was established in 1987. Its basic mission is to offer a free service

to the public where up-to-date information and expert assistance is available. The Reference Service division provides personal access to database information and to other services offered by the Clearinghouse. An important database maintained by the Clearinghouse is its "Resources Database." This is a database which covers over 6000 AIDS-HIV related organizations and services and which lists contact phone numbers, description of services, and key personnel. Another interesting source is its "Educational Materials Database." This service provides bibliographic information about HIV and AIDS educational materials such as brochures, directories, fact sheet, information packages, manuals, books, posters, reports, study and teaching guides, sound recording, videotapes, book chapters, and advertising campaign materials. It gives special attention to locating and listing audiovisual materials, especially videotapes and sound recordings. All materials listed which contains sexually explicit language are identified and described. Materials in this database are suitable for both the general public as well as special groups.

Libraries are eligible to use these two resources. All they must do is to ask for the free computer program which operates the system. When the program first began , CDC made the assumption the computer hardware would be available locally to access these databanks. This was not always the case. To encourage wider participation by information agencies, including libraries, the CDC for a time offered a series of small grants to libraries and other agencies so they could acquire the computer hardware necessary for participation. To my knowledge, few libraries have asked for this assistance.

Another interesting information resource is the National AIDS Hotline. This also operates as a part of CDC. The clearinghouse is designed to allow sensitive questions to be asked in an anonymous and confidential manner with as much detail as possible. The hotline provides a format which is personal, comfortable, and safe. The complete service is offered in both English and Spanish. Access for the deaf is also provided. Information specialists who respond to inquiries have access to a special database developed by the hotline staff. The staff can use this database to make referrals regarding such issues as hospitals, legal service, testing sites, and counseling and support groups. Libraries can play a role in this hotline by knowing that it is available and by providing information as to how to get to it.

Part IV. Examples of Programs

Although American libraries for the most part have been willing to purchase books and nonprint materials relating to AIDS-HIV in accordance with their overall material selection policies and goals, survey data indicate that only limited specialized programs and services have been established regarding AIDS information. Nevertheless, some of these programs are quite impressive. In the remaining part of my talk I shall attempt to provide some example of specific library-based programs which offer or have offered better-quality AIDS information programs in the United States.

I would like to begin with community-based programs. I define community-based library programs as those programs which are not attached to any government, but which arise from and are formed within the community. Many, if not the majority, of the AIDS-based services programs in the United States are community-based, and most of these claim to have an information component, including a library. But it is my feeling that few of these have libraries which meet any level of professional management standards. There are exceptions such as the Wisconsin AIDS Library, the Detroit AIDS Library, The AIDS Committee of Toronto Canada, and the AIDS Information Network of Philadelphia.

The AIDS Information Network of Philadelphia and the AIDS Committee of Toronto are outstanding examples of AIDS information service libraries. The AIDS Information Network describes itself as a specialized library open to the general public with little or no restrictions. It claims to have the only comprehensive collection of information specially devoted to HIV-AIDS in the United States. The library collection contains books, clippings, posters, pamphlets, videotapes, periodicals, newsletters, CD-ROMs; and it has expanded its electronic network of services in recent years.

The staff collects materials suitable for the general public, specialists, and for children and adolescents. The library also maintains an extensive collection of materials for free distribution, including sexual and drug-explicit materials produced by many organizations. There are two basic components: the library-unit and the telephone-based information and referral service. The information and referral service is considered the front line of service as it addresses most of the immediate questions which come to the network.

One of its most valuable resources is its information file which contains well over 75,000 items dating from 1981. This file is constantly being updated and it is organized according to subject headings developed by the Network especially for this file. The Network has also developed a unique classification scheme for its book and nonprint collection.

In addition, the network offers the "safeguard" program and the "Critical Path AIDS Project." The safeguards program is a sexuality and safer-sex program directed at "men who have sex with other men."

The AIDS Committee of Toronto Library has been in operation since 1983. It is considered a central part of the intake and counseling operation the organization. It has a collection of approximately 14,000 items, including books, videotapes, periodical subscriptions, an information file; and it offers access to electronic databases . Clearly it is one of the largest collections of HIV-AIDS materials in North America. It has developed its on classification scheme which is available for sale. The collection is open to the public and it offers reading, viewing, photocopying, and consulting facilities.

The Wisconsin AIDS Library is a division of the AIDS Resource Center of Wisconsin. It is funded largely from a CDC program designed to provide a central resource of AIDS information in each state. In addition to a collection of books, nonprint items and periodical subscriptions, it subscribes to a clipping service which allows it be maintain an impressive information file which dates from 1986. As I just stated, because it is funded by CDC, its major responsibility is to provide HIV-AIDS information to the entire state of Wisconsin.

The Rick Rednor AIDS Library is located in Trenton, New Jersey; and it provides an interesting example of community-based organization library. It is a small library which collects specifically HIV-AIDS information. It is an independent organization with its own board of directors although it is housed in the Mercer Medical Center Foundation in Trenton. It was started by Rick Rednor who died of AIDS in 1991 and it is continued in honor of his memory. It is supported by contributions and various fund-raising activities. Although the library has a small collection of materials the staff is proud that it has been able to automated its circulation system. It is open to the public and serves largely the medical and school communities.

The Information Center of the AIDS Services of Austin (ASA) is a community-based organization which has just reorganized its library collection. I was fortunate enough to be asked to consult on this reorganization plan and I would like to share with you some of my observations with you.

First of all we in Austin are indebted to Jean Hofacket, Director of Information of the Philadelphia AIDS Network for giving us the inspiration to reorganize this library. Jean came as a speaker at an AIDS Information Day sponsored by the Graduate School of Library and Information Science and after hearing her speak and describing the work being done at the Network, the educational staff at ASA wanted a similar service. In the course of a year the library was reorganized along lines suggested by Jean. For example, we adapted the Network's classification scheme and information file subject heading list for our own use, and we cataloged all of the book collection and some items in the nonprint collection. The director of information services applied for a grant under the *Ryan White CARE Act* (*Ryan White Comprehensive Resources Emergency Act*, 1990) and with that money she was able to expand the collection and to also buy an online catalog system. In addition to the online catalog of local materials, the library now offers access to the Internet and the World Wide Web as well as several other databases such as AIDSLINE. It is also developing its own home page for the World Wide Web.

With all that said, I must tell you that within recent months, the management of ASA has changed and a new philosophy has emerged. As of November 6, the new management eliminated the educational unit as well as the position of director of information services. Although the information center remains, I cannot tell you what its future will be.

The Ron Shipton HIV Information Center, located on the West Hollywood Branch of the Lost Angeles Public Library was among the first public libraries in the United States to develop a special collection for AIDS information. West Hollywood has one of the highest HIV infection rates in the United States and it is a center of gay and lesbian culture. An estimated 30 percent of its population is gay or lesbian. From the beginning, the mission of the center has been to serve the general public, the health, legal and professional communities, local government agencies; and the gay and lesbian community with information in a safe and bias-free environment.

The library staff was given the freedom to select materials which included books, magazines, periodicals, pamphlets, and videocassettes. In addition, it has provided access to CAIN—the Computerized AIDS Information Network developed by Los Angeles Gay and Lesbian Community Service Center. Unfortunately, in recent years the Los Angeles Public Library has been hard hit with budget reductions, and the Center consequently has had to cut back services and to acquire less materials.

Another interesting public library program is the Sussex County Library located in Newton, New Jersey. It has no formal AIDS program, but its librarians have responded in several ways to HIV-AIDS information needs. This effort is spearheaded by Margaret Bailey who is Coordinator of Branch and Extension Services. Bailey is closed involved with the HIV-AIDS service community in Newton through her volunteer work. With her encouragement, librarians make effort to find and purchase materials which serves the general public, the HIV community, the worried well, families and friends of HIV-AIDS affected people and health professionals. The collection is diversified and includes such topics as personal narratives, basic AIDS information; materials on how to live with HIV; death and dying issues; grief and bereavement; community and business planning; counseling; spiritual and pastoral concerns; legal issues; government benefits; literature including poetry, fiction, and essays; guides for teachers; volunteerism; bibliographies photo essays and art; directories; government document; and young adult and juvenile literature. In an effort to expand resources, the staff regularly searchers HIV-AIDS related and gay and lesbian publications.

V. Models for Service

My observations tell me that libraries will respond to the AIDS crisis and that American librarians believe that they have a responsibility to provide reliable information. But responses will vary. Based on what I see occurring within the United States today, I have developed three models of service which I feel can provide reasonable response patterns to the need for HIV-AIDS information within the American library community. Simply stated, the models are Basic AIDS Information services; Mid-level HIV-AIDS Service; and Advanced HIV-AIDS Services.

The basic model calls for the library to develop a collection which emphasizes consumer health, general health care, and social and cultural health issues. I suggest that libraries that follows this model

devote considerable attention to collecting materials on the sociological, psychological and cultural impact of HIV-AIDS. I advise that libraries collect trade books for adults and youth, that they buy general and selected specialized HIV-AIDS reference materials, and that they pay attention to building their pamphlet or information file coverage. As videotapes are now the favored form of audiovisual materials, libraries may wish to devote considerable attention to building a videotape collection for children, adolescents, and adults. Libraries will want to make sure that a wide assortment of general periodicals which are likely to deal with HIV-AIDS issues are available. They will also need to develop finding aids such as reading listings and bibliographies to help users locate needed information.

In terms of programs and service, I suggest that they pay attention to the needs of youth. They should make sure that information about community services are available in the library and that HIV-AIDS materials are not unduly restricted. They will also want to provide for the distribution of free HIV-AIDS materials. On occasion, with the help of HIV-AIDS experts, they might help present special programs and exhibits on HIV-AIDS. As facilities allow, they can offer library quarters to community-based groups for programs. Libraries can also become apart of public information marketing campaigns by having the library mentioned as a good source of reliable HIV-AIDS information; and they should be willing to respond in positive ways when the public reacts to that type of information campaign by requesting materials and information from libraries.

In addition to the service pattern suggested in the basic model, the mid-level model requires more attention be paid to the information needs of both specialists and people personally associated with HIV and AIDS. To do this, I suggest that libraries acquire selectively scholarly and technical books about HIV-AIDS and subscribe to specialized and technical periodicals, newsletter, and reports. Libraries will also need to pay special attention to information supporting the emotional needs of HIV-AIDS suffers, their families, and friends.

For libraries following a mid-level approach, I suggest that they become involved with community-based groups and that they identify a network of experts within the community so that specialized referrals can be made. Libraries can also become involved with HIV-AIDS experts in developing and presenting a variety of workshops, lectures, and film programs.

At the advanced level of service I suggest that libraries move into highly specialized types of programs and be prepared to offer a wide variety of programs and services. This may include on-demand computer searches and Internet access. Libraries may wish to address the informational and educational needs of specialized groups such as health professionals and community organizations. For example, they might offer review and examination services of HIV-AIDS materials for health professional. Some staff members might even write reviews of materials for publication and they might prepare special bibliographies and finding guides for the use of HIV-AIDS experts and service managers. They might also offer consulting services to community-based organizations regarding their information programs. In essence libraries following the advance-level model will want to integrate themselves as much as possible into the broader HIV-AIDS service community and take part in a variety of outreach activities. It seems to me that the configuration of an advanced program at the local level will be determined by the past history of the library as an institution, immediate local needs, management considerations, staffing and funding availability, the overall library philosophy and mission of the library, and the energy and professional commitment exhibited by the staff.

Another important role which libraries can play is the housing of archival collections produced by AIDS-HIV service organizations within the community. For example, the New York Public Library has arranged to house the archives of the Gay Men's Health Crisis Inc. (GMHC). This is important because the GMHC was one of the first organizations to arise in response to this health crisis in the United States and probably in the world. Today it is one of the major producers of AIDS-HIV information and educational materials. The records of this organization will be crucial to understanding the social, cultural, and educational aspects of this disease in the future. Other archival collections in the United States which contain AIDS-HIV information include the AIDS Information Network of Philadelphia which houses the Peter Carey papers. This is a collection of materials which not only deal with the early years of the AIDS crisis in New York City but which also reflect the development of gay and lesbian political and social movement from 1981 to 1993. Similarly the manuscript collection in the library at Cornell University contains an extensive amount of primary materials which relate to political experiences and reflections of individuals who were affected by AIDS. This collection also houses the papers of the

National Gay and Lesbian Task Force. These papers are important because this organization devoted considerable attention to developing national policy positions and political intervention strategies during the formative years of AIDS. The library at the University of California at San Francisco manages the AIDS History Project. This project, with the funding of the National Historical Publications and Records Commission is an attempt to secure historical documentation of the responses to the AIDS crisis in San Francisco. Over time, the project will identify, record, and deposit in appropriate research facilities the official records of agencies that have been involved in this crisis. This will include government agencies as well as community-based organizations.

VI. Conclusion

In concluding my remarks I feel that I can safely say that many positive actions have been taken by libraries in the United States to provide HIV-AIDS information to the public. Nevertheless many problems and issues remain. As I mentioned earlier, the mass media in the United States is beginning to say that the threat of AIDS was overstated in the early years of the crisis and that the impact has not been as great as was feared or expected. This view seems to be based on the fact that the disease has not become wide-spread within the heterosexual population. How will this perception affect the commitment of American librarians to HIV-AIDS information? Will it influence how Americans as a whole come to regard the need for HIV-AIDS information? Only time will tell.

Even if American society manages to maintain a national commitment to eradicating the AIDS disease, one important question remains: will American librarians as a professional group be willing to become more proactive in their dissemination of health and HIV-AIDS information? Whenever we find an active HIV-AIDS program in a library we usually find individuals who have a personal or social commitment to lessening the effects of this disease. We must therefore ask whether American librarians as a group are ready and willing to alter their traditional information-neutral role in society and become more active in promoting information services designed to correct and change social behaviors and attitudes. As I have said, some librarians have done this to be benefit of many. They have done so with a sense of immediacy which recognizes the current health crisis; and they have done this within the traditions of librarianship. I think they have proven that the traditional methods of librarianship can

work well in facing modern challenges. It is indeed rare that American librarians as a profession have been given such an important role to play in a crisis which involves information, education, and life.

Thank you again for providing me with this wonderful opportunity to be with you. It is certainly one of the highlights of my professional career.

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References

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[1] U.S. Centers for Disease Control figures as quoted by Mary Ann Lindley, "AIDS Seemed Even Scarier in '87, Knight-Ridder Newspapers, September, 1996.

[2] Tara Burghart, "One in 300 Americans Has HIV, Study Says," Associated Press, September, 1996.

[3] Judith Segal, "The Academic Library and Social Responsibility: A Focus on AIDS," *Journal of Academic Librarianship* 17, 224-29, (Sept. 1991). 224-29.

[4] Judith Segal, quoting Nicholas Freudenberg, Jacalyn Lee, and Diana Silver, "How Black and Latino Community Organizations Respond to the AIDS Epidemic: A Case Study in One New York City Neighborhood," *AIDS Education and Prevention* 1, (1), 16, 1989.

[5] J. Ingrid Lesley, "Libraries and the AIDS Crisis: Information Is the OnlyVaccine," ALA Yearbook, vol 13 (Chicago: American Library Association, 1988), 158, quoting Lowell Levin from a speech given 27 June 1987, American Library Association, San Francisco, California.

[6] Diana Gonzáles Kirby and Tony A. Harvell, "U. S. Government Information Policy and the AIDS Epidemic," *Government Publications Review* 16 (March/April 1989): 161, 163.

[7] Grant Lukenbill, *Untold Missions: Positioning Your Business for the Gay and Lesbian Coonsumer Revolution*. 1st. ed. (New York: HarperCollins, 1995).

[8] Mark Hochhauser and James H. Rothenberger, *AIDS Education* (Dubuque, Iowa: William C. Brown, 1992), 106-7.

[9] Public Library Association, Community Information Section, *Guidelines for Establishing Community Information and Referral Services in Public Libraries* (Chicago: American Library Association, 1989).

[10] Margaret I. Rufsvold, *Audio-Visual School Library Service: A Handbook for Librarians* (Chicago: American Library Association, 1949), 49.

[11] Ruth Ann Davies, *The School Library Media Center: A Force for Educational Excellence* (New York: R. R. Bowker, 1969) 78-79. [This concept carried on in her later editions as well]; and Phyllis J. van Orden, *The Collection Program in Elementary and Middle Schools: Concepts, Practices, and Information Sources* (Littleton, Colorado: Libraries Unlimited, 1982) 73-85.

[12] Texas Education Agency, *Community Resources File in the Learning Resources Center* (Austin, Texas: Texas Education Agency, 1990).

[13] Terence Brake, *The Need to Know: Teaching the Importance of Information. Final Report for the* Period *January 1978 - March, 1978.* British Library R & D Report 5511. (London: British Library, 1980).